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ABSTRACT

The practicum developed a four-part program to promote a community support network to meet the needs of head injured children and their families. A primary goal was to increase the membership in the head injury support group and provide a network of community support for this population. A second aim was to increase the awareness of head injuries in the community at large. Initial interviews with 14 parents of head injured children revealed that the support group focused on the needs of the adults but parents felt that attending meetings only deepened their feelings of frustration and helplessness. The intervention program consisted of: (1) a multi-media awareness and prevention program; (2) an awareness and prevention program for grades 4, 5, and 6 and local service organizations; (3) an awareness and prevention program to educate state and local legislators; and (4) a program to update physicians on the activities, goals, and objectives of the support group. Results were generally positive with increased support group attendance, increased numbers of phone calls to the support group, and increased knowledge about head injuries in the target groups. Extensive appendixes include the parent interview information, program evaluation data, attendance and phone call documentation, press releases, and the head injury prevention and awareness program presentations for school children and service organizations. Includes 23 references. (DB)

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AN AWARENESS PROGRAM TO INCREASE THE COMMUNITY SUPPORT NETWORK FOR HEAD-INJURED CHILDREN IN GRADES K-12 AND THEIR FAMILIES

by

Sidney L. Payne

Cluster XXIII

A Practicum II Report Presented to the ED.D Program in
Early and Middle Childhood
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Education

Nova University

1990

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ABSTRACT

Improving support group services for head-injured children and their families.

Payne, Sidney L., 1990: Practicum Report, Nova University Ed.S. Program in Early and Middle Childhood. Descriptors: Head Injury / Traumatic Brain Injury / Pediatric Head Injury / Severe Closed Head Injury / Support Groups / Community Agencies / Head Injury Awareness / Head Injury Prevention.

Interviews with 14 parents of head-injured children revealed that the goals of the community support group are focused on the needs of the adults. Parents indicated that attending these meetings only deepened their feelings of frustration and helplessness.

The primary goal of this practicum was to increase the membership in the head injury support group and provide a network of community support for this population. A second aim was to provide community of an awareness of the impact of head injuries and how they can be prevented.

The writer designed and implemented a four part program designed to promote a community support network to meet the needs of head-injured survivors, their families, and significant others. The program consisted of a multi-media awareness and prevention program, an awareness and prevention program for grades four, five and six and local service organization, an awareness and prevention program to educate state and local legislators, and a program to update physicians on the activities, goals, and objectives of the support group. The results of the practicum were positive.

Chapter I

Introduction

Description of Community

The community is which the practicum will took place is a resort community in southwestern United States. It is often referred to as "The Entertainment Capital of the World" and claims the largest resort hotels in the world. A growing tourist and convention industry, along with new manufacturing industries, has resulted in the population doubling over the last ten years. Today there are over half a million residents. It is the largest city in the state.

Besides the resorts, the community is home to one of the two state universities. This university has one of the most superior hotel colleges in the United States and as a result attracts students from the entire country. The university is in the center of the residential community and provides residents with an Allied Arts Council, symphony orchestra, a professional ballet company and one of the country's top rated basketball teams.

The socioeconomic make-up of the community runs the gamut. Like any major metropolitan city there are areas of extreme poverty as well as great affluence. The majority of the community, however, would be considered middle class. Because it is a resort community, the population is more transient than most communities.

Writer's Work Setting and Role

The county in which the practicum was conducted comprises one school district which has an area of 7,910 square miles. The district operates 134 schools which include 94 elementary schools, 5 special schools, 19 junior high schools, and 16 senior high schools. A bond issue was passed in December of 1988 in which the voters passed a $600 million bond issue with plans to construct 77 new schools over the next ten years to accommodate the projected growth.

The school district is managed by a seven member Board of Trustees who are elected for four-year terms. The district employs 10,100 full-time persons. An estimated 5,500 of them are certified, 320 are administrative personnel, and the remainder, approximately 4,300, include bus drivers, clerical workers, custodians, cafeteria workers, and teachers aides.

Student enrollment for the 1988-89 school year was 105,176. Nearly 59 percent of all school children in the state, kindergarten through grade 12, are enrolled in this school district.

The district operates special programs for the academically talented, visually handicapped, aurally handicapped, orthopedically handicapped, mentally retarded, slow learners, emotionally disturbed and homebound education.

The district also provides vocational and technical training, speech therapy, psychological and social worker services, nursing services, teacher aides, counseling and guidance programs, drug and anti-alcohol education programs, remedial reading programs, and career education programs.

State law requires school attendance between seven and 17 years of age. Kindergarten is part of the regular school program but is not compulsory. A child must be five years old on or before September 30 to enter kindergarten. A child must be six years old on or before September 30 to enter first grade.

The school district is racially integrated. Seventeen year-round elementary schools are in operation. Bus transportation is furnished to students living two or more miles from school, kindergarten excepted. Report cards are issued for nine-week periods for first through 12 grades and at the end of each semester for kindergarten.

The amended final operating budget for the 1988-89 school year was $350,280,342.00. Support from the state provides about 45.9 percent of the budget. Federal aid and other sources provide 7.7 percent. Combined support for local sales tax (26.5 percent) and property tax (19.9 percent) equals 46.4 percent. Per pupil expenditure is estimated at $3,263.47.

The writer's background has been deeply embedded in developmental education. The writer holds an undergraduate degree in psychology and a master's degree in special

education. The writer is certified by the Department of Education in the following areas: 1) mild to moderate mental handicaps, emotional handicaps, and learning disabilities k-12, 2) physical handicaps k-12, 3) secondary education in psychology, 4) substitute in regular education k-12, and 5) substitute in all areas of special education k-12.

The writer has taught in the present school district for the past eight years, three years as a substitute and five years as classroom teacher for physically handicapped children. Presently the writer holds the position of Facilitator of Special Education at a comprehensive high school.

The duties of the writer's present position are many. The writer is responsible for six resource rooms and five special programs. The special programs include two classrooms for mentally handicapped students, a program for severely emotionally handicapped students, a program for severely learning disabled students, and a program for severely physically handicapped students.

The primary responsibility of the writer is to maintain all records for the special population and ensure that procedures are followed. The writer is also responsible for the development and implementation of new curriculum and vocational programs to meet the diverse needs of the school's special education population. The writer also serves as dean and counselor for this population,

serves as department chair, and is responsible for the special education budget.

Along with the duties in the school district, the writer presently serves, and has served in the past, as president for the local head injury support group. This is a non-paid position. The involvement of the writer with this organization is a direct result of the many head-injured children placed in the writer's classroom for the physically handicapped children.

The local support group was established nine years ago by six parents of head-injured survivors who banned together in their struggle to overcome the devastating effects of head injury upon their children and their families. In the nine years the support group has been in existence the members on the mailing list has gone from 6 to 380.

As the membership expanded, so did goals of the organization. Today the support group works to promote the goals of the National Head Injury Foundation, Inc.:

1. Increase public, family and professional awareness of the silent epidemic.
2. Advocate to achieve recognition of the problem of head injury and the needs of those of those who have suffered head injuries.
3. Create an information and resource center for head injury.
4. Develop a unifying structure to provide support for the survivors of head injury and their families.
5. Assist in the establishment of rehabilitation programs for the head

injury population - from coma to community.

6. Raise monies to support research.

7. Prevention.

The support group is presently being governed by an executive board of directors which includes the writer as president, a vice president, a past president, a secretary, a treasurer, and six board members. Of the executive board, four members are in the educational system and provide services for head-injured children, two board members are adult head-injured survivors, four board members are parents of adult head-injured survivors, and one board member is a parent of a head-injured child.

The writer has been an extremely active volunteer in other community and professional organizations serving disabled children and adults for the past fifteen years. The writer is presently a member of the planning board for the local Association for the Handicapped and serves as a consultant for the local Computer and Technology Center for Disabled Children and Adults. The writer presently serves on a number of different task forces. One is a school district task force to improve education for head-injured children. Another task force is the Head Injury Task Force with the community Association for the Handicapped. The third task force is a local Disabilities Task Force which is composed of service organizations and community health care providers working toward meeting the needs of the disabled. The writer is also a member of the personal care attendant

eligibility board for the local chapter of United Cerebal Palsy. The writer is a board member of the local chapter of the Council for Exceptional Children and responsible for the production and editing of four yearly newsletters.

In the past the writer has been honored by the governor for many hours of volunteer service to mentally handicapped children. The writer has also been honored by the Muscular Dystrophy Association as an outstanding activity coordinator at the regional summer camp for two consecutive years. Being the recipient of two Excellence in Education Awards and being honored as "Educator of the Year" have been the writer's most cherished moments in education. The first Excellence in Education award was expressed by The Special Education Parent Advisory Committee for continually being nominated as an outstanding teacher. The writer's second Excellence in Education was recently presented by the writer's school district for "Transitioning the Severely Physically Handicapped Student to the Community College." This year the writer was awarded the distinguished honor of "Educator of the Year" by the local chapter of the Council for Exceptional Children.

CHAPTER II

STUDY OF THE PROBLEM

Problem Description

Head injury in the United States has reached epidemic proportions. The Interagency Head Injury Task Force Report of February 1989 states that every fifteen seconds someone in the United States receives a head injury. Every five minutes one of these people will die and another will become permanently disabled. It is the leading cause of death and disability in children and adolescents.

Primarily a disability of the young, traumatic brain injury takes a tremendous toll on society. The economic costs alone approach $25 billion per year. A survivor of a severe head injury typically faces 5 to 10 years of intensive services at an estimated cost in excess of $4 million. Paradoxically, research into the control and treatment of traumatic brain injury receives less than one penny of every federal dollar spent on medical research.

The Center for Disease Control (CDC) in Atlanta, Georgia serves in a unique role as a leader and catalyst in injury control by bringing together the diverse groups necessary to establish truly collaborative efforts to reduce injuries. The National Academy of Sciences (1988) reports that head injury is

the most underrecognized major public health problem facing the nation today.

The CDC established the Division of Injury Epidemiology and Control in 1985 to create a federal focus for injury control and to coordinate the national agenda in prevention, epidemiology, biomechanics, rehabilitation, and acute care. This division was established following the 1985 publication of the National Academy of Sciences landmark document, Injury In America. This document identified the public health importance of injuries and the need for injury control, research, resources, and organization.

A head injury, however, happens to families, not just the individual. The burdens that occur for families with a traumatically brain-injured member and the important role of the family in the rehabilitation of these patients is clearly recognized (Bishop & Miller, 1988). Limited attention, however, has been given to the emotional and psychological needs of the family members and significant others during this long period of rehabilitation.

The needs of head-injured children and their families appear to be neglected by the health care systems. In the writer's state there are only three rehabilitation centers. Upon discharge from one of the state's three acute rehabilitation units there are no comprehensive community programs for head-injured

children or adults. None of the three rehabilitation units are designated pediatric units. To the writer's knowledge there is only one pediatric physiatrist licensed to practice in the state. This physiatrist, who lives in a neighboring state, holds a clinic twice a month at the university medical center. As a result most children are integrated with the adult population. They are, unfortunately, treated as "little adults". Since the majority of the rehabilitation specialists in the writer's community work primarily with adults, they have little awareness of community services available to the head-injured child or their family. Information given to family members by the hospital, usually focuses on the adult head-injured survivor rather than the child who survives a head injury. All three hospitals have a hospital social worker. The social workers are overburdened in all three hospitals and do not have time to spend with families.

Families are left with few options for support and services. Families who can afford outside help have difficulty locating professionals trained in pediatric head injury rehabilitation. Those that cannot afford outside services or out-of-state placement at facilities that specialize in pediatric head injury rehabilitation are often left with fragmented services for the survivor and few support services for the family. Even if families do send their children to

out-of-state facilities the family remains in the community without support.

There is a lack of a community support network for head injured children, their parents, family members, and significant others in the writer's community. This problem will be addressed by this practicum.

Problem Documentation

The writer, who is president of the local head injury support group, was contacted by the Department of Human Resources, Division of Developmental Disabilities, concerning the number of calls and letters their offices have received from family members inquiring about community services and support groups for head-injured survivors, their families, and significant others.

A head injury support meeting is held on the third Wednesday of every month at the university medical center. Notices of the meetings are mailed a week in advance to all individuals on both mailing lists. A review of the monthly attendance rosters from support meetings from January 1989 to January 1990 indicate that an average of 20 people attend support meetings (Appendix A).

An examination of the support group records revealed the names of 21 school age children under the

age of 14 who have suffered a severe head injury. These parents were contacted by phone and asked to answer five questions about their involvement in the support group (Appendix B).

Results of the interviews (Appendix C) revealed that the writer's available information was not correct. Only 14 members were under the age of 14. The average age in this group of 14 children was 8.6 years.

Analysis of the parent interviews of children 14 years and under reveal that the majority of parents do not take an active part in the support group because the meetings are too stressful. Most of these parents feel they cannot handle the stress of listening to the tragedy of others. They feel it is all they can do to keep handle their own situation.

Six parents feel that the group does not focus on the needs of children. Since the majority of the members are young adults most activities and speakers are directed toward their needs and not that of children. Parents of head injured children feel their needs are quite different from the needs of the older population.

Four of the parents contacted feel it is too late for a support group to help them. Their children are severely disabled and are permanently living out of the home. These families are attempting to put their lives

back together and do not wish to be reminded about the loss of the child they once knew. Ironically, none of these four parents wished to have their names removed from the mailing list.

Three of the parents interviewed did not find out about the support group until after their children were well on the road to recovery. They stated they could have used a support group at the time of injury but do not need a support group now. All three parents did request to have their names remain on the mailing list to receive updated information on head injuries.

Two parents have no way to transport their children or any one to stay home with their children should they wish to attend. Both are single parents and both indicated that they would really enjoy attending if their problem could be solved.

One parent feels that support groups are nothing more than a group of individuals who would rather "bitch and complain" than take responsibility for what God had handed them.

Causative Analysis

The passive involvement of pediatric head-injured survivors, parents, and family members in the Head Injury Support Group is believed, by the writer, to have many causes. Perhaps the most important cause is that many survivors and family members are unaware that the support group exists. During the eight years that

the group has been in existence it has always operated out of the homes of one of the officers. The group has had six different telephone numbers and mailing addresses since it was established. Since the phone number has always been the private line of the president of the support group, there is no listing in the phone book for a head injury support group. Individuals who are aware that there is a support group are often unable to obtain the phone number to ask for assistance.

Another cause is that the present objectives of the support group are not being implemented. This is not surprising in light of the fact that the organization operates on an all volunteer staff. All persons on the executive board are currently employed full-time with the exception of one parent. As a result services provided are extremely limited. Presently the services and programs offered are for young adults between 18 and 30. The needs of young children and older adults are not addressed. The only program for family members of children is a "Parent Education Program to Improve Parental Involvement in IEP's for Severely Head-Injured Children in Grades 1-12". Although this program has proved to be extremely successful over the past two years it does not address the needs of children and families before

the child enters school. No programs are offered for older adults.

Another major cause is the lack of support by the professional community. Physicians and rehabilitation specialists in the community seldom refer patients to the support group. Although the professionals will address the group when asked, they still do not refer patients. In the eight years since the group was established, printed material that defines the goals and objectives of the group has yet to be developed. The only written material ever made available to professionals has been a business card with the president's phone number.

A fourth cause arises from the fact that many individuals who could benefit from the support group are emotionally unable to deal with attending the meetings. Physicians seldom make positive comments concerning the prognosis a head-injured child. Their less than positive attitudes are met with parental resistance. Attending a support meetings often implies a realization that the the physicians and health care professionals may be correct in their prognosis.

A fifth cause is that many family members are unable to transport their head-injured child or have no one to stay with the child while they attend the meeting. Most children with recent injuries are in wheelchairs and these parents do not have wheelchair

vans available for transporting their child. Although we have wheelchair taxis in the community, taxi fare is extremely high for already overburdened parents.

A sixth cause is that individuals turn to support groups for guidance and referral services. When parents turn to the support group for guidance only to find out few services are available, they hold the support group responsible for not doing an adequate job. They do not want to hear suggestions from other family members on how to provide rehabilitation at home. What these parents want and need are services that are unavailable in the community. When the support group explains that these services do not exist, these parents often turn away.

A seventh cause is a lack of focus. Every individual that attends the support meetings arrive with their own agenda. Since parents and family members are in different stages of recovery, from different cultures, and from different financial backgrounds, their needs are significantly different. Bringing family members together to support one and other often depends on a common cause in which all members can relate.

A final cause that seems to affect the majority of non-profit organizations is a lack of a financial base. One of the goals of the support group is to provide a central clearinghouse for information and

resources. Without financial assistance the support group library is small and offers little to families. Since the cost of head-injury rehabilitation is devastating to most members, funds generated from the membership are sparse. Fund raising has had little success due to the small number of members who are able to become involved. In a non-profit organization fund raising has two purposes. The first is that it brings in revenue for the organization, and second it brings attention to the organization. Many individuals are informed about this type of an organization through the publicity involved in the fund raising process.

Related Literature

Injuries are the leading cause of death and disability among young children and young adults in the United States. Injuries kill more American between the ages of 1-34 than all diseases combined and are the leading cause of death of all persons through age 44 (Injury in America, 1985).

The real devastation of a severe head injury, however, is not death but surviving with a permanent disability and the inability to lead a fully productive life. Two-thirds of children who become comatose after traumatic brain injuries survive, while only half of those older than 15 years of age survive (Lehr, 1990).

The higher rate of children who live after sustaining significant head injuries makes the importance of appropriate services even more crucial. The disabilities following severe brain injury encompasses physical, cognitive and psychological deficits which preclude thousands of young children from returning to normal preinjury life activity.

It is important to recognize that as medical technology has advanced, it has become increasingly possible to survive with serious disabilities over the long term, when in the past such disabilities might have resulted in death. In 1960, the average person with a severe brain or spinal cord injury could expect to survive only a few years with serious disability. By the 1980's, however, the expected survival period had increased to 35 years with new methods to prevent secondary complications from infection. In 1990 and beyond it is anticipated that the average victim with a severe disability will have nearly a normal life expectancy (Rice, 1989). These disabled survivors will put further strain on the ability to provide human care, long-term medical and rehabilitation services, and community programs because of a lack of resources and cut-backs in state and federal funding.

Words cannot express the fear, anguish and despair of head-injured survivors and their families. A substantial amount of literature has been devoted to

the emotional reactions and needs of severely head-injured children and adults. In contrast, little attention has been given to the emotional needs and reactions to the child's family (Waaland & Kreutzer, 1988). This is ironic in light of the fact that family members and significant others are usually the primary care giver and are responsible for coordinating and carrying out the treatment plan provided by the health care givers. Except in unusual circumstances, families and significant others are essential in the recovery and eventual functioning level of the child (Lehr, 1990).

Foster, Berger, and McLean (1981) point out that when working with families of children after they have suffered a head injury, it is important to bear in mind that "family" is not synonymous with "parents". The entire family must be considered including siblings, grandparents, aunts, uncles, cousins, and other relatives who are important to any one particular family's functioning. It cannot be assumed that there is necessarily a united family perspective about how the head-injured affects family interaction and contributes to family stress. Each family member has an individual reaction and way of coping with the child's injury. This reaction impinges and alters family functioning, just as the head-injured child's functioning also affect family interaction.

The problems resulting from the severe impairment of a family member are compounded by frustrations of trying to work with medical, legal, and social systems that, are for the most part, not equipped to deal with either the immediate or long-term consequences of surviving with a significant disability. Many families find that the present system discourages efforts toward self-sufficiency and provides no support for the family as a unit (Lehr, 1990; Department of Health and Human Services, 1989)

Marilyn Spivack, the mother of a head-injured daughter, founded the National Head Injury Foundation, Inc, in 1980 upon the realization that support for head-injured survivors and family members was virtually nonexistent. Until the establishment of the NHIF, no single existing federal, state, or private agency concerned itself exclusively with the unique problems faced by head-injured survivors and their families. "Until NHIF, this 'lost population' was silently and shamefully closeted away, and inappropriately placed in psychiatric institutions, schools for the retarded, or nursing homes (National Head Injury Foundation, Inc., 1980.)"

For some families the financial burdens of hospitalization and rehabilitation are overwhelming. This financial stress, added to the already stressful situation, is often the breaking point for many

families. When a family member has to deal with the insurance company or the legal system it often involves a recapitulation of the events surrounding the accident. Feelings that family members thought were in the past and could be partially forgotten reemerge and can often threaten the family stability (Lehr, 1990).

Ten years ago there was no agency which concerned itself exclusively with the unique problems faced by the head-injured survivor and their family. Today, however, there are over 500 agencies serving the needs of this population. Many of these are excellent facilities, unfortunately, many are not. The average daily cost for a post acute rehabilitation facility that specializes in head injury rehabilitation is between four and five hundred dollars a day, excluding the cost of the physician and psychologist. This in itself adds a new stress to family members. Determining which facility is the most appropriate is often an impossible task for a family member during this difficult time (Lehr, 1990).

Often by the time a head-injured survivor leaves the acute setting, insurance dollars have been depleted. This leaves the family without financial resources to continue rehabilitation, without options, without any support, and often without hope. Families who have been self-sufficient now must turn to society for assistance (DeJong & Batavia, 1989).

Providing help and support to families is often difficult as pointed out by the "Command Performance Syndrome" (Sbordone, Kral, Gerard, & Katz, 1983). An SCL-90 self report inventory was administered to 41 significant others of head trauma patients undergoing inpatient rehabilitation. Data from this inventory, along with clinical observations and interviews, suggest that the significant others tend to manifest a "Command Performance Syndrome" in which they appear relatively "normal" and suppress their emotional distress in the presence of the patient and health care professionals. Further investigation, however, revealed that virtually all of these significant others made a deliberate effort to appear "strong" in the presence of health care professionals but frequently began to cry as they left the hospital each evening. They indicated that they were "falling apart inside" and were unable to sleep at night and ruminated constantly about the patient's condition. Sbordone and his colleagues conducted a similar study with a group of significant others who were seeking outside support and treatment. The results of this study suggested that those seeking outside help and support were more willing to admit feelings of distress than those who were not seeking help.

Ylvisaker (1985) reported that parents and family members pass through several stages in their

attempt to cope with the child's head injury. Initially parents face the shock of having the life of their previously healthy child hanging by a thread. Once they know that the child will live, they begin to receive frightening warnings about the changes in their child.

Hutzler (1980) states that this loss is as real as if the child had died, yet it is more complex. When parents become fully aware of their child's needs and the changes in their child, they are inevitably shocked. They must suddenly adjust to the loss of their child as the knew him or her. The child that they once knew is gone and a stranger somehow inhabits the body they have watched grow since birth. The personality that they had nurtured is also altered, perhaps beyond recognition. These parents pass through the grieving process that involves shock, anxiety and helplessness, denial, guilt, anger, and depression (Poliniko, Barin, Leger, & Bauchman, 1985).

A prospective study done by Rutter, Chadwick, and Shaffer (1983) suggests that the initial impact on the parents of their child's severe injury was considerable. Parents had doubts about whether their children would survive the severe injury. About half of the parents were described as experiencing persisting emotional disturbances of their own in reaction to their children's injury.

Research by Brooks (1984) suggest that a head injury in the family usually results in a disruption of family relations, a shift in social roles within the family and general adjustment problems. Brooks also stated that family members report abdicating customary social and home routines since the family believes its continuation might cause undue stress for the head-injured person.

A study by McKinlay, Brooks, and Bond (1981) reported diagnostically significant levels of depression within the first month of injury. They stated that the length of the patient's hospitalization, the number of the patient's reported problems, and the duration of posttraumatic amnesia were positively correlated with family member's levels of depression.

Livingston, Brooks and Bond (1985) completed a similar investigation that focused on the first three months of postinjury. The psychiatric status and social status of relatives of severely injured patients were compared with that of relatives of patients who had sustained mild injuries. Findings were consistent with expectations. Although depression levels were similar in both groups, relatives of severely head injured manifested significantly more anxiety than relatives of patients with less severe injuries.

A seven year study on a sample of 134 persons with brain injury and their families who were examined at a range of 2 to 7 years postinjury suggests that the duration of posttraumatic amnesia was statistically established as a predictor of family burden. The greater the duration of posttraumatic amnesia, the greater the burden reported by family members (Brooks, Campsie, & Symington, 1987).

Rutter, Chadwick, and Shaffer (1983) reported an increase in marital tensions initially after injury. These tensions appeared to subside within a few months. Lezak (1988), however, did not report the same findings. Lezak found a high incidence of divorce in parents of severely injured children.

Some parents and individual family members are so devastated by the child's injury that they do not have enough energy to care for the child during recovery. At times there is a severe reaction to "guilt" by the family members who feel the accident was their "fault". This feeling is often an added stress on already overburdened individuals (Lehr, 1990).

Studies that have been published regarding the needs of the families after head injury are difficult to compare. The research spans different cultures and different populations. In these studies a wide variety of assessment techniques have been utilized. There is no doubt that the family of a head-injured child is

under a significant burden, however, the burden is easier to appreciate than to define and measure (Livingston & Brooks, 1988).

In conclusion, the problems of providing support for the head-injured child and their family is not one that can be easily solved. The dynamics involved with the head-injured child and the many stages that parents and family members go through during the recovery and the rehabilitation of a head-injured child are diverse. Professionals, health care providers, and community service agencies must become allies with the family of the head-injured individual in their goal to provide support to restore the family unit.

CHAPTER III

ANTICIPATED OUTCOMES AND EVALUATION INSTRUMENTS

Statement of General Goals

Meeting the needs of parents and family members is as important to the recovery of the head-injured child as meeting the needs of the child. Just meeting the needs of the head-injured child often decreases the stress on the parents and family members. Providing services and support for head-injured children and their families, however, is a team effort. Families, health care providers, and the community must work together. The writer's projected goals were to increase participation and membership in the already existing head injury support group. The writer's second projected goal was to provide public awareness of the physical, emotional, cognitive, and financial consequences of a head injury. The writer's third projected goal was to provide the state and local legislators with information concerning the long-term needs of the head-injured survivors and their families. The fourth and final projected goal was an all encompassing goal to promote head-injury prevention strategies. To quote Marilyn Spivack, founder of the National Head Injury Foundation, Inc., "Prevention - The Ultimate Cure."

Behavioral Expectations

Objective One

Over a period of six months attendance at support group meetings will increase from an average of 20 to 30 members a meeting.

Objective Two

Over a period of six months incoming telephone calls on the helpline will increase from an average of 15 to 30 telephone calls per month.

Objective Three

Over a period of six months students in a minimum of 60 classrooms for fourth, fifth, and sixth graders and members in a minimum of 30 service organizations will demonstrate an increased knowledge of the causes and consequences of a traumatic head injury by responding correctly to four out of five items on a questionnaire developed by the writer.

Objective Four

Over a period of six months 80 percent of state and local legislators will respond to a survey to assess their position on the need for state funded services for head-injured survivors and their families.

Objective Five

Over a period of six months 80 percent of the local pediatricians, neurologists, psychiatrists and neurosurgeons will respond to a survey to assess whether they are regularly providing their head-injured patients and their families with information on the services, activities, and goals of the local head injury support group.

EVALUATIVE INSTRUMENTS

Objective one was measured by utilizing the present system of documentation for meeting attendance (Appendix A) and a new member application form (Appendix F).

Objective two was measured by utilizing the present incoming phone documentation system (Appendix E) and phone roster (Appendix D).

Objective three was measured by a writer-made questionnaire entitled "Heads You Win" (Appendix G). This measure is made up of five multiple choice questions. Questions were presented one at a time utilizing a slide projector. Individuals responded as a group by a show of hands. Responses were recorded utilizing a form developed by the writer (Appendix H). The person who requested the presentation evaluated the

effectiveness of the program on a form developed by the writer (Appendix I).

Objective four was to be measured by the number of surveys returned by state and local politicians. The survey was to be developed and approved by the support group executive board.

Objective five was measured by the number of surveys returned by local pediatricians, neurologists, psychiatrists, and neurosurgeons. The survey was developed and approved by the support group (Appendix O).

MECHANISM FOR RECORDING UNEXPECTED EVENTS

Due to the extended length of time this project covered, the writer kept a daily journal. This journal was used to record what was working well and what was not working well. The journal was also used to record comments from those participating in the program. The journal served as a guide for continual improvement of specific aspects of the practicum.

CHAPTER IV

SOLUTION STRATEGY

Discussion and Evaluation Of Possible Solutions

Head injury rehabilitation, as a specialty, is a relatively new phenomenon. Until the establishment of the NHIF in 1980, no single existing federal, state, or private agency concerned itself exclusively with the unique problems faced by the head-injured survivor and their families.

The problems facing this population have been embraced by the NHIF. The NHIF and its state charters and affiliates are a membership organization composed of those families, friends, medical and social service professionals concerned with the physical and emotion well-being of head-injured survivors and their families. The NHIF is a non-profit agency supported by membership dues, fund raising events, contributions and grants. Today there are 31 state associations, 6 state affiliates moving toward association status, 375 local support and education groups. The NHIF has over 16,000 members and a mailing list of over 47,000. Disseminating information and stimulating development of service providers around the country is an essential task that has been taken on by the NHIF. This organization is dedicated to the restoration and

maintenance of the dignity of life for the victims of this "Silent epidemic".

Much from the work of the NHIF, head injury rehabilitation is a recognized specialty and as a result there are over 500 agencies, which include state, federal, and private agencies, that serve the needs of this population. Head injury rehabilitation is a $1.2 billion industry (Bush, 1988). Despite this statistic, only 1 of 15 persons who experience a head injury receives rehabilitation. Obtaining funding for head-injured survivors and their families is a problem of great magnitude.

Since the establishment of the NHIF the needs of the families is beginning to be looked at more closely. Works by Brooks (1984), Foster, Berger, and McLean (1981), Hurtzler (1984), Lezak (1988), Lehr (1990), Livingston & Brooks (1988), provide a helpful framework for understanding parental and family reactions. All discuss the importance of family involvement as part of the rehabilition team and the importance of recognizing the impact of the head injury on the entire family. When Bush (1988) points out, however, that only 1 in 15 head injuries have the funding to receive rehabilitation, the chances of the family receiving services are slight. In light of this reality, the burden of restoring the family unit is assumed by the local support group.

The financial problems facing the nation concerning head injury rehabilitation will be increasing as a result of more head-injured individuals surviving. Improvements in emergency room practice, diagnosis, and surgery allow more head injured patients to survive (Department of Health and Human Services, 1989). The work of the NHIF, affiliates, charters, and support groups will need to be increased in order to meet of this growing population.

States that are charter member or affiliates of the NHIF, by the nature of their membership, have become strong lobbying forces to provide services for the head-injured survivors and their families (Bush, 1988). The majority of the states that provide comprehensive services for the head-injured and their families have, for the most part, extremely active support groups. These states are active participants in influencing public policy and legislation.

In order to have an active support group you must have an active membership (Spivack, 1988). The programs and activities needed by this population will only become a reality if the support group has an active membership. This requires individuals to take an active leadership role. The NHIF has recognized the importance of leadership in the establishment strong support groups and as a result held the NHIF First Annual Leadership Training Seminar in August of 1989 in

Minneapolis, Minnesota. According to Marilyn Spivack (1988) support groups without strong leadership are not effective in making the changes that are necessary for the group to become successful.

Ms. Spivack has assisted many support groups in there quest to become state charters. According to Ms. Spivack, the first step in this process in increasing the active membership of the group. According to the NHIF, the most effective way to develop an active support group is through a community program in which all members can participate, regarless of their age or needs. Parents and family members often feel helpless in meeting the needs of their head-injured family member. Becoming involved in a community program which focuses on the common needs of all the membems often becomes the catalyst in creating the bond that is necessary for a strong foundation.

The NHIF keeps files on community projects that have been developed and implemented by its state charters and affiliates. These are available to support groups for implementation in their state. The writer has reviewed the programs, along with community programs from many of the leading research centers for head injury in the United States. Many of these programs are excellent, however, most are geared toward the specific community where the program was developed. The New York support group, which is one of the

strongest in the country, has produced an excellent awareness and prevention program which emphasizes the need to wear a helmet when riding a bicycle. In the writer's state, however, the local bicycle club is presently running a helmet campaign and stressing the importance of helmets. The goal of this program is not only to stress safety but to increase the membership in their bicycle club. These public service announcements are tagged with the bicycle club's phone number and not that of the head-injury support group.

Since the majority of head injuries are a result of motor vehicle crashes, seat belt campaigns have been implemented in most states. Seat belt campaigns have been successful in reducing accidents. Most public service announcements for seat belt use do not discuss the long term consequences of a head injury. Death is the ultimate consequence stated in these announcement for not wearing your seat belt.

Bigler (1987) reports that the most successful injury prevention strategies are passive ones in which agents, vehicles, or environments are changed to automatically protect the population at risk. Air bags and automatic seat belts are examples of passive restraints (Werner, 1988). These methods, however, are not favored by the majority of the public and may be viewed by the community as "radical".

Increasing membership by developing and distributing a state pamplet has proved successful to all state charters of the NHIF (Spivack, 1988). This has been so successful that it is now a criteria to develop a state pamphlet as one of the requirements of becoming a state charter. Although the NHIF has a national pamphlet, personalized state pamphlets give members a feeling of accomplishment in their steps toward self-advocacy

Installing a separate telephone line for the head injury support group, which is listed in both the white pages and the yellow pages, is another criteria of the NHIF in the goal of becoming a state charter. Most support groups begin with their first meetings in the home of a family member of a head-injured survivor. As a result, the general public, unless they have been given the private phone number of that individual, have no way of knowing that the support group exists.

Increasing membership through fund raisers has often been a strategy utilized by non-profit organizations. These fund raisers can be exceptionally successful with the right publicity. This is not, however, an avenue that would probably result in success in the local support group. With such a small active membership, the stress of attempting a major fund raiser could drive away the existing membership.

Increasing the membership is not going to be an easy task. It is going to be extremely important to maintain a positive approach reaching the public. A head injury from an accident is not one that individuals are willing to give much thought. The prevailing attitude is that it is not going to happen to me or someone I love. Most individuals feel that accidents resulting in a severe disability are the types of accidents that only "happen to others."

Description of Selected Solution

The solution, to having an active support group for head-injured children and their families, was based on several of the strategies which were discussed earlier in this chapter. An increased membership provides for greater interaction among parents and family members of head-injured survivors. This is the true essence of a support group. Increasing membership in the local support group is also a means of providing a strong lobbying force. This lobbying force is a vital key to obtaining appropriate services in the community for the head-injured survivors and their family. Restoring the family unit after the tragedy of head injury is a challenge that must be met.

Many of the strategies discussed in the chapter have contributed excellent suggestions and were redefined to meet the needs of the writer's community and incorporated in the writer's solution strategies to solve this problem.

The solution strategy, which was employed to increase the membership, was a four part program. These programs were partially funded by a grant from the State Department of Human Resources, Rehabilitation Division. This department recognized the need for a strong support group and provided funding through a grant to assist in the following goals:

1. A multi-media awareness and prevention program.
2. An awareness and prevention program for grades four, five and six and service organizations.
3. An awareness and prevention program for state and local legislators.
4. A program to update physicians on the activities, goals, and objectives of the support group.

REPORT OF ACTION TAKEN

The Multi-Media Program

The media has been a proven avenue of gaining public attention. In the writer's community there are head-injured individuals and their families who are unaware that a local support group exists and that other families are in the same situation.

A media campaign, in order to be successful, must reach the community in a positive manner. With poverty, homelessness, and AIDES continually in the media, the public does not wish to hear any more sad stories. As a result, the programs which were chosen to reach and inform the public of the existing support group was an awareness and prevention program.

The goal, of this aspect of the program, was to increase the membership and the number of incoming

phone calls. Both the new membership application (Appendix F) and the incoming phone documentation system (Appendix E) asks for documentation to how the individual found out about the support group. This documentation gives the support group information on the most effective means of providing the public with information about the support group and upcoming activities.

Television - Radio - Newspapers

Press releases were sent to the television stations, the top six radio stations in the city, and the local newspapers about upcoming events of the support group (Appendix Q). Each press release ended with vital information about head injures and a prevention message. Press releases reached the media ten days prior to the event (Appendix R).

Each press release also had the association phone number included. Prior to sending the first press release, the support group installed a business phone line for the organization. The number was listed in both the white and yellow pages. Until this time the phone number was the number of the president of the support group. As a result, the number was not available from information unless the individual knew the name of the president.

The phrase "HEAD SMART" was adopted by the board of directors to be used in every message. The hope of

the board was that this would become a positive message for children and one that both children and adults would remember if heard often enough.

The support group had hoped that the television and radio stations would provide the group with a list of the times and days when the messages were aired. This service, however, is only provided when the time slot is being purchased. Public service announcements and community bulletin board services were played at the stations convenience. As a result, the writer did not know whether the press releases were aired.

The support group had also hoped that at least one of the television stations would produce a local prevention message featuring a child from the community. This, unfortunately, did not happen.

In September, a board member of the support group contacted the head of public relations director at the university medical center. The writer, along with the board member, made an appointment with the director to discuss the lack of television coverage concerning head injury prevention. The director was aware of the support group's prevention program and offered assistance in obtaining television coverage.

In October, the support group had a Candlelight Vigil as part of a program sponsored by the National Head Injury Foundation, Inc. to bring public attention to the causes and devastating consequences of head

injuries. The director of public relations from the hospital contacted a local news network to cover the Candlelight Vigil. As a result the new network compiled a news feature for both the 6:00 news and the 11:00 news. Several members of the support group were interviewed. As part of their story they did a live interview with the writer. The writer closed the interview with the statement, "Since life is never the same after a head injury. Prevention is the ultimate cure." The station taped another interview with the writer for the 11:00 news and once again the writer was able to interject a prevention message. It was clearly evident that the goal of the television station was to report, not only on the tragedy of head injuries, but prevention. Without the assistance of the public relations director of the university medical center, this would not have been possible.

The two major newspapers printed the press releases every month in the community calendar. The press releases, however, were always edited. They reduced the copy to cover only the basics. To the writer's knowledge, the prevention message was never printed in the newspapers.

The same press releases were mailed to the radio stations. Originally, the board of directors was going to hand carry the release to the stations. This proved

to be a hardship for the board in light of their other duties, so the releases were mailed.

Press releases, along with meeting announcements, and legislative updates were always printed on the same color of post card. All post card carried the message, "Address Correction Requested - DO Not Forward". All postcards always had a prevention message printed on the address side of the card. Print ready prevention messages were obtained from the National Head Injury Foundation, Inc. and the National Safety Council.

The Awareness and Prevention Program

Many states have implemented awareness and prevention campaigns. Most of these programs are a combined effort by many agencies with a goal of reducing the number of injuries. Although prevention is a primary goal of these campaigns, the success in terms of preventing accidents is almost impossible to calculate. It is easy to count the bodies of those who do not survive a head injury but it is difficult to count those accidents that are prevented because of awareness campaigns. A 1990 objective of Center for Disease Control (CDC) includes injury prevention. The CDC has established, for the first time, an on going surveillance and analysis of injury mortality and has established the foundation for a national coalition of

organizations that have commitments to injury. Five regional centers around the country have been established for this purpose.

Since it is impossible to measure the effectiveness of this program in terms of accidents prevented, the program was measured by the increase in knowledge of the causes and consequences of head injuries demonstrated by the individuals attending the prevention program (Appendix G). The results recorded on the audience response sheet (Appendix H) served as a record of the schools and organizations visited.

The program was made available to forth, fifth, and sixth graders attending year round schools (Appendix S). A similar program was also made available to service organizations (Appendix T). The basics of the program were the same, the dialogue was changed to accommodate the specific audience.

The announcement of the availability of the program was to be placed in both local newspapers along with the school district "Hotline", which is received by every employee in the school district. The program, however, was never advertised. Word-of-mouth was the only advertisement needed. During the course of the practicum the writer presented the program to 69 fourth, fifth, and sixth grades and 33 service organizations for a total of 102 presentations

(Appendix P). The writer currently has presentations scheduled through January of next year.

The program is a 50 minute program which includes a stimulating slide presentation describing the consequences of a traumatic head injury received by a child living in the community. The slide presentation takes the audience from the accident back to school. The presentation is a longitudinal study of a young head-injured girl who was a student in the writer's classroom four years ago. The student was 10 years old at the time of injury and is now 15 years old. At the time of the accident the student was running into street to chase a ball. She was struck by an automobile driven by a speeding teenager. The student was hit head on, flipped over the car, landed on the trunk, and then fell to the ground. The student suffered a severe closed head injury, several broken bones, and was in coma for two months. The student was in a wheelchair for two years. The student is now ambulatory and back in a regular high school. Telegraphic speech and left side neglect are still evident.

The writer chose to develop this presentation because there were none of this type available commercially that dealt with children. The only commercial programs that the writer was able to locate concentrated on the 15 to 24 year old population. The

writer felt these were not appropriate for children. The writer also felt that a personalized presentation was far more effective.

The program was presented by the writer. A head-injured individual always accompanied the writer. This individual "personalized" the presentation by sharing his or her experience. The writer selected the head-injured survivors who participated very carefully. All survivors were able to speak with the audience and communicate their stories. The student in the slide presentation, along with her sister, attended 18 of the presentations.

When presenting to children the writer always had a member of the bicycle club, skateboarding club, or a roller skater present. This balanced the presentation for children. Speaking with someone who excels in their favorite sport and practices safety is far more meaninful than listening to an adult "preach about safety". The writer also had a display of the latest in bicycle helmets and safety gear for the audience to view. Discount coupons for approved bicycle helmets, provided by the university medical center and a bank in the community, were given to each individual who attended.

The writer also utilized handouts from a prevention book produced by the New York Head Injury Association entitled, Head Injury Prevention Goes to

School. Permission may be obtained to reproduce the handouts from this program through a contribution to the New York State Head Injury Association. This association actively invites groups to become "Partners in Prevention". Handouts from the book may be reproduced with the name, address, and phone number of the organization distributing the handouts. The only stipulation by the New York Head Injury Association is that the copyright notice be left intact.

Handouts utilized by the writer from this program included a "Teacher Alert" which was provided to all teachers. Service organizations were provided with a handout entitled, "Because There Might Be More To Head Injury Than You Thought." The children were provided with handouts from this program entitled, "Most Bike Riders Who Die - Die of Head Injuries" and "Skateboarding: Do it Safely". Copies of several other of the handouts were left with teachers to be distributed at later dates to reinforce safety procedures to prevent head injures. These included safety procedures for trick or treating, swimming, riding in a car, and sledding. All individuals received the state pamphlet.

Awareness and Prevention for Legislators

The writer's state is greatly lacking in services for the head-injured population largely due to a lack of funding for rehabilitation services. A legislative interim study committee recently researched the problems facing the head-injured and their families. The legislature selected the head-injury study as a result of the lobbying efforts of the two head injury support groups in the state.

Whether or not the recommendations of the interim study committee for head injuries are voted upon positively in the next legislative session will be dependent upon the continued lobbying efforts of the two support groups. One of the recommendations of the committee is to get a state registry for head injuries. Since we presently do not have a state registry, the actual numbers of head injures is not known. A study, recently completed by the Department of Human Resources, depended on the facilities and organizations which presently serve the head injured for their statistics. A second recommendation will be to provide state funded comprehensive services for head-injured survivors and their families. Presently, individuals requiring these services must go out of state or do without. It is important that the governor, state senators, and state assemblyman are aware of causes and

the devastating consequences of head injury and the needs of the community before the next legislative session in January 1991.

To accomplish the task of educating legislators about the causes and devastating consequences of a head injury the support group provided the individuals with information on head injures. Three mailings instead of the intended six mailings were completed. Since this was an election year, it was the optimal time to educate the representatives.

The first mailing was sent to everyone who was presently holding an office. The mailing contained a cover letter, a fact sheet (Appendix L), and a state pamphlet (Appendix J). The second mailing, which went to all individuals running for office, contained a cover letter and the prevention pamphlet (Appendix I). The final mailing was sent out after the primary election. The final candidates received a mailing which included a cover letter, a fact sheet (Appendix L), a business card, and the state prevention pamphlet (Appendix I). The executive board of the support group concluded it was best to send the same information over and over to reinforce the information. The dates of the mailings were as follows:

1st Mailing	June 5
2nd Mailing	August 15
3rd Mailing	September 12

A survey was to be developed and sent to all legislators to access their position on the need for state funded services for head-injured survivors and their families. This was not developed. State monies cannot be utilized for the purposes of lobbying. This would have put the support group in violation of the grant and jeopardized the remainder of the project.

Physician Update Program

In an attempt to get local physicians to refer head-injured individuals and their families to the support group, the support group supplied each psychiatric, neurologist and nuerosurgeon with 50 copies of the state pamphlets and 50 of the prevention pamphlets (Appendices J & K). The pamphlets were developed and designed by the writer and approved by the support group executive board. The pamphlets were personally delivered by members of the executive board.

Following the delivery of the pamphlets the physicians received monthly meeting updates for head-injured survivors and their families (Appendix U). On the fifth month the physicians received a survey (Appendix O). The survey asked physicians if they wished to be listed in a Directory of Head Injury Services being developed by the writer. The survey contained a question as to whether the physician

regularly shared information about the support group with their patients. Physicians were asked to return the survey in the stamped envelope provided.

Originally pediatricians were to be included in the monthly mailing. The board concluded that since the pediatrician was not the physician treating the head injury, to include them on our monthly mailing list was not cost effective. The board did, however, send one mailing to all pediatrians which included the state pamphlet and the prevention pamphlet.

These projects could not have been completed without the assistance of the disabled community. The data bases for politicians and physicians were entered into the computer and saved to disk by the learning disabled high school students in the writer's school district. The thousands of materials placed in the mail were collated, stamped, and labeled by mentally handicapped students. The assistance of these students was invaluable.

CHAPTER V

RESULTS, CONCLUSIONS, AND RECOMMENDATIONS

Results

Objective one was measured by comparing support group attendance for the months of May to October of 1989 (Appendix A) to attendance for the months of May to October of 1990 (Appendix M). The objective of increasing attendance at the support group meetings from an average of 20 to 30 members a meeting was not met. Membership was increased by an average of 8 members per meeting instead of 10 members. The objective was not met.

Table 1 summarizes the comparison.

Table 1. Assessment of Meeting Attendance

Month	Attendance 1989	Attendance 1990	Member Increase
May	12	27	15
June	33	33	0
July	9	16	7
August	12	12	0
September	26	36	10
October	44	62	18
Total	136	186	50
Mean	23	31	8

Objective two was measured by comparing the number of phone calls to the support group for the months of May to October 1989 (Appendix D) to the number of phone calls to the support group from the months of May to October 1990 (Appendix N). The objective to increase the average number of phone calls from 15 to 30 per month was met.

The writer was extremely pleased that this objective was met. An increase of an average of 20 phone calls per month exceeded the expectations of the support group. This rise in phone calls proved to be more than the writer was able to handle. Between prevention presentations, guest lecturing, a full time teaching position, involvement in other community programs, and an increase of over 50 percent in phone calls, the writer was unable to complete all duties. As a result, call forwarding was installed on the office telephone and calls are were often forwarded to other members on the executive board.

Having calls forwarded to other members of the executive board brought the board closer together as a team. Often being part of an executive board only means attending meetings and paper work. Members who have received phone calls have expressed a stronger desire to increase their involvement as active members. Table 2 summarizes the increase in phone calls to the support group.

Table 2. Assessment of Incoming Phone Calls

Month	Total Calls 1989	Total Calls 1990	Number Increase
May	23	24	1
June	15	27	12
July	4	28	24
August	12	37	15
September	14	44	30
October	40	69	29
Total	108	229	121
Mean	18	38	20

Further analysis of incoming phone calls gives the writer a clear indication of which portions of the practicum project should be continued. Of 124 first times callers, approximately 40 percent received information from the pamphlets, 16 percent received the information from the newspaper, and 15 percent received the information from the phone listing. Table 3 provides the source of information for first time callers.

Table 3. Sources of First Time Callers
May 1990 - October 1990

Month	TV	Radio	Newspaper	Pamphlets	Phone Listing	Physicians	Other	Total
May	0	0	3	6	3	1	1	14
June	0	0	2	8	2	1	2	15
July	0	0	1	10	2	1	5	19
August	0	0	2	9	4	0	3	18
September	0	0	5	7	2	2	5	21
October	3	0	7	9	5	1	12	37
Total	3	0	20	49	18	6	28	124
Percent	2%	0%	16%	40%	15%	5%	23%	

Objective three was measured by a teacher-made questionnaire entitled "Head Smart" (Appendix G). The objective was for individuals to demonstrate an increased knowledge of the causes and consequences of a traumatic head injury by responding correctly to four out of five items on the questionnaire. This objective was clearly met on every occasion.

During the course of the writer's presentation the information in the questionnaire was repeated continually. Both children and adults had no difficulty answering four out the five questions. Not only were they able to answer the questions, but their enthusiasm indicated that they had truly internalized

the information and that the information had became a frightening reality. Children and adults both left the room repeating the fact to one another that every 15 seconds a head injury occurs in the United States. Every single person met the criteria. Table 4 summaries the number of prevention presentations.

Table 4. Summary of Prevention Presentations

Month	Fourth Grade	Fifth Grade	Sixth Grade	Service Organization
May	0	0	0	8
June	10	3	13	6
July	6	9	12	5
August	12	8	6	10
September	0	0	0	2
October	0	0	0	2
Total	28	20	21	33
		69 total		

Objective four was to be measured by a survey developed by the executive board. The goal was that over a period of six months 80 percent of state and local legislators would respond to a survey to assess their position on the need for state funded services for head-injured survivors and their families. A

formal survey was not developed, therefore, the objective was not met.

The survey was not developed because the major funding for this project was provided through a grant from the State Department of Human Resources, Rehabilitation Division. It is prohibited to use money from a state grant for the purposes of lobbying. The goal was to educate legislators about head injuries, the lack of services in the writer's community, and the devastating effects of severe head injury on the survivor, family members, and society. The long term goal of this education program, however, was to influence their decisions in the next legislative session. Since there is a fine line between educating legislators and lobbying, the executive board chose not to develop a survey. Although the formal survey was not developed, the support group still followed through on their original plan to educate legislators in this election year.

The Governor's Committee on Employment of People With Disabilities, along with our support group, and several other groups who advocate for the disabled, sponsored "Candidates Night". Fifteen local politicians were present and interviewed by members of the support group executive board. All stated that they had received the information from our group and were aware of the devastating effects of head injury.

Our response that evening would indicate that the efforts of the group had been successful.

Objective five was measured by a physician's survey (Appendix O). The objective was for 80 percent of all local pediatricians, neurologist, psychiatrist, and neurosurgeons to respond to a survey to access whether they are regularly provide their head-injured patients and their families with information on the services, activities, and goals of the local head injury support group. The goal as written was not met. It was determined by the board of directors that adding all local pediatricians to the mailing list and providing them with continual information was not within their funding base at this point and time. Forty-seven pediatricians are listed in the yellow pages. These pediatricians were, however, part of a one time mailing and received a copy of both the state pamphlet and the prevention pamphlet. Both pamphlets contain membership applications. The support group operated on the assumption that if pediatricians wanted to be part of the organization or required more information, they would return the application or phone the office. To date only one pediatrician has become a member of the organization.

Although most head-injured children do have a pediatrician, it is the neurologist, neurosurgeon, or psychiatrist that treats the head injury. As a result

the board determined that only the neurologists, neurosurgeons, and psychiatrists would be surveyed. The objective was met for these physicians at 93% percent. Twenty-seven neurologist, neurosurgeons, and psychiatrists are listed in the yellow pages. Each received a survey (Appendix O) along with a stamped envelope in which to return the survey. The writer utilized an old ploy of politicians to ensure the return of the surveys. Along with assessing if the physicians were regularly providing their head-injured patients with information about the support group, the cover letter explained that the support group was compiling a directory of head injury resources in the area. The physician's were informed that if they wished to be included in the directory they needed to verify that the information on the letter was correct. Twenty-seven surveys were mailed. Twenty-five of the twenty-seven have been returned. Of the twenty-five surveys returned, all checked that they wanted to remain on the mailing list as the regularly share information about the Support Group with their head-injured patients and their families.

CONCLUSIONS

The full results of this practicum indicate that the community is not only becoming aware of the

devastating results of a head injury but are realizing the need for prevention education. Although significant gains have been made in the writer's community over the past several years in meeting the needs of the head-injured survivor and their family, much still needs to be done.

The first and second objectives were concerned with increasing membership. The goals of informing the community of the activities of the support group and spreading the prevention message were continual. The importance of a multi-media approach cannot be overstressed.

The information that individuals received through the mail was extremely important. Utilizing the same color post cards for meeting notices, press releases, and legislative updates proved invaluable. Post card messages were short and to the point. This has been recognized by the organization to be extremely effective. It proved to be an inexpensive way to gain immediate recognition. Members continually comment that when they see a blue post card in the mail they are aware that there is an important message from the support group.

Placing the notation "Address Correction Requested, Do not Forward" proved to be extremely helpful in keeping the mailing list up to date. This suggestion was provided by the National Head Injury

Foundation, Inc. and has proved to be an excellent one. Before this message was printed on materials mailed, mail would be returned to the office with the message, "Forward Expired." At this point we would lose track of the individual.

The manpower needed for a project of this scope is great. This project could not have been completed without the support of the disabled community. Several high school classrooms for resource room students and mentally handicapped students participated in assisting the head injury support group. Having these handicapped students assist in this operation was mutually beneficial for several reasons. First they provided the manpower needed to complete the tasks at hand. Second, they were provided with real-life work opportunities. But even more important, the need to prevent head injuries was continually reinforced as each piece of mail handled contained a prevention message. Since mentally handicapped students are at a higher risk of head injury as a result of impaired judgment, the continual reinforcement to prevent injuries and practice safety appeared extremely beneficial. All students who provided assistance received a certificate of appreciation from the support group. This was an inexpensive way to say thank you to these dedicated students and provide them with recognition for their support. The students appeared

to take great pride in their ability to take part in a program that benefited so many in the community.

The writer became aware, late in the project, of the necessity of establishing bonds with the public relationships department at the university medical center. Until the writer's organization made an appointment with the public relations director, the organization was not successful in getting the local television stations to air prevention messages. We were successful in getting our meetings announced on the community bulletin boards, but not successful in getting the prevention message aired. Very early in the practicum the writer became painfully aware that every service organization in town was attempting to get their message aired on television. It was not until a good working relationship was established with the university medical center public relations department, that the writer's organization was successful in getting television air time for prevention messages.

The third objective was concerned with informing the community of the effects of a traumatic head injury and to spread the prevention message. The way in which children and adults live and play is changing rapidly. Their bicycles, skateboards, and rollerskates are far more sophisticated and faster than they have been in the past. Traffic is increasing at an alarming rate.

Pedestrians and vehicles are competing for the same space. It is imperative that children and adults be educated in safety procedures and the need to wear helmets and protective gear when participating in these activities.

It became very apparent early in this project that if children and adults are going to listen to a prevention message it had to be somewhat entertaining. Involving members of the community who are successful "high risk takers" or "fun seekers" in the prevention presentation appeared to be extremely effective. When the so called "Wild Ones" promoted the safety message, children and adults responded. Providing samples of the latest safety equipment and allowing the individuals to become active participants only served to enhance the presentations.

The organization quickly became aware of the need for a speaker's bureau. The original intention of the writer was to advertise in the local newspapers and the school district hotline that the prevention program was available. This did not happen. Word-of-mouth in the community was all that was necessary. The writer was unable to fulfill all the requests for presentations. At present, the writer has speaking engagements scheduled through the first of the year. A speaker's bureau would strengthen the message of the support and reach a greater number in the community.

The fourth objective was to survey state and local legislators to access their position of the need for state funded services for the head-injured survivors and their families. Although this goal was not met, the efforts of the support group in keeping the legislators updated on the devastating effects of head injury upon society is to be commended. Whether or not the efforts of this group were really successful will be determined at the close of the next legislative session. Through the efforts of the State Department of Human Resources, Rehabilitation Division, this organization, and the community, several bills will be presented to the state legislature. Whether or not these bills are passed will serve as measurment of success.

The fifth objective was to survey physicians serving the head-injured population and determine if they regularly provide their head-injured patients and family members with information about the support group. This objective, although not met in terms of the criteria of this practicum, was successful in the eyes of the support group. Providing physicians which serve the head-injured with updated information on the activities of the group appeared to be extremely beneficial. The personal involvement of the board of directors in hand delivering much of the information also appeared to be quite successful. This not only

gave the board members the opportunity to make contact with the nursing staff but saved a significant amount of postage. The writer feels that the personal contact with the physicians's office demonstrated the commitment of the support group in their goals.

The support group could not have made the gains in community support without the support of the State Department of Humane Resources, Rehabilitation Division. A grant was submitted by the writer and approved. The grant provided funding to cover the cost of sending four members to Washington, D.C. to attend the national convention. It also covered the cost of a business phone installation, the monthly phone bills, the cost of printing the pamphlets, postage, and office supplies for the year. The support group will be eternally grateful to the state for their belief in the group's commitment. Their financial support, along with the dedication of the rehabilitation staff, allowed the organization to gain recognition in the eyes of the community and the facilities which support head-injured survivors and their families.

The grant from the state was a "start-up grant". The support group realized from the beginning that this grant was not going to be renewed. Under the recommendation of the National Head Injury Foundation, Inc., the organization has sought funding from several sources for the next fiscal year. Operating the

diversified programs of the support group on a sole source of funding proved to be extremely difficult. The grant obtained by the writer was for not only the activities of the writer's support group but for the support group in the northern part of the state. This proved to have its problems. As a result the writer's support group spent only a portion of what had been intended in order to provide the northern support group with the remainder of the funding base.

Marilyn Spivack, founder of the National Head Injury Foundation, Inc., continually cautions support groups on the danger of state funds as the sole source of funding for operating expenses. Should the funding be cut, the organization has lost their entire funding base. As a result, the support group has submitted grants to several different organizations to provide funding for the next fiscal year. The success of the program this year, however, was a direct result of the state grant. It provided a firm foundation on which to build.

The writer feels that the support network established among the members and the professional community is invaluable. Head injury rehabilitation and prevention is a community concern. Bringing professionals, legislators, family members, and head-injured survivors together has served to build a strong foundation.

In conclusion, the goal to increase the community support network for head-injured children and their families appear to have been successful. Although not all expectations of the writer of the writer were obtained, the overall results indicate that the common bonds to working together as a community have been found. Professionals in the community have gained the knowledge of the goals and objectives of the support group. The support group feels they have gained the support of the professional community. Not only are these groups working together to provide much needed services for the head-injured survivors and their families, they are working together to prevention future injuries.

RECOMMENDATIONS

The writer has several recommendations based on the results of this practicum. First, an awareness and prevention campaign is not something that can be done over a period of six months and then forgotten. For this campaign to be truly successful it must be a continuing and ongoing project.

The second recommendation is to include individuals in the prevention presentation that are respected by the students and whose performance exemplifies the practice of safety. Utilizing members

of the local bicycle, skateboarding, and rollerskating clubs truly enhances the prevention message.

The third recommendation is that support groups develop a speaker's bureau within the organization and the community. One or two speaker preaching the prevention message is not enough for an entire community.

A fourth recommendation is for the support group to establish a supportive relationship with all the local hospitals. Positive working relationships with the local hospitals sends a message of community commitment.

A fifth recommendation is to provide all physicians in the community with a copy of the state pamphlet and a business card on a yearly basis. Physicians, even those who do not typically serve the head-injured population, could prove to be a vital referral source and should not be overlooked.

A sixth recommendation is to provide all contributors to the support group with recognition. Thank you notes and certificates of appreciation should be standard procedures.

A seventh recommendation is to place the notation, "Address Correction Request - DO NOT FORWARD" on all materials mailed from the office. This procedures keeps the mailing list and records up to date.

An eighth recommendation is to print a prevention message on all mail that is distributed by the support group. This is an inexpensive channel to spread the prevention message.

A ninth recommendation is to select a specific color of post card to be utilized for all meeting notices, press releases, and legislative updates.

A tenth recommendation is to utilize disabled individuals in the community to assist in the daily operations. This provides these individuals with vital job training and allows them the opportunity to become active participates in an advocacy for the needs of the disabled.

An eleventh recommendation is to fund a project of this size and magnitude through the use of many sources. A single funding source could put a project like this in jeopardy should the funds become unavailable.

A twelfth recommendation is to become active politically. The changes needed to meet the needs of the community will require active political involvement in local, state, and federal legislation.

A final recommendation is to have the slide presentation utilized developed commercially. This would allow for greater dissemination.

Dissemination

The results of this practicum will be shared with the head injury support group in the northern part of the state. The state pamphlet (Appendix J) and the prevention pamphlet (Appendix K) have already been shared with this group. The prevention program itself was presented to the executive board along with suggestions on how to develop a slide presentation about a member or members from their support group.

The full results of the practicum will also be shared with the National Head Injury Foundation, Inc, its state charters and affiliates. The state pamphlet and the prevention pamphlet have already been shared with these groups. Four individuals, two from the northern support group and two members from the writer's support group, attended the fifth annual National Head Injury Foundation, Inc. Conference. Funds for their attendance were provided under the state grant. The conference, "Building the Future," was held in June in Washington, D. C. The four members distributed the pamphlets and explained our prevention program to all state charters and affiliates.

The full results of this practicum will also be shared with the local PTA, Girl Scout Council, and Boy Scout Council. The writer will also share the full results of this practicum with the local chapter of the

Council for Exceptional Children. The writer's hope is that these organizations will assist in the continuation of the prevention message.

The results of this practicum were recently shared with a group of over 300 individuals in attendance at the National Safety Council's 75th Annual Congress and Exposition. Over 16,000 were in attendance at the congress. The writer was asked by Marilyn Spivack, founder of the National Head Injury Foundation, Inc., to participate on a panel to discuss the needs of head-injured survivors and their families. Whenever the writer addresses an audience on the topic of head injuries, the platform is always closed with the need for prevention. Since life is never the same after a severe head injury the writer feels compelled to spread the message of Marilyn Spivack, **"Prevention - The Ultimate Cure".**

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APPENDIX A

SUPPORT MEETING ATTENDANCE
JANUARY 1989 - JANUARY 1990

Meeting Attendance

January 1989 - January 1990

Month	Pediatric Survivor or Family Member	Adult Survivor or Family Member	Prof.	Other	Total
January Support Meeting	0/1	3/5	1	0	10
February Guest Speaker Speech Pathologist	0/5	6/8	9	3	31
March Support Meeting	0/1	5/6	2	0	14
April Support Meeting	0/1	8/10	1	0	20
May Support Meeting	0/0	4/6	2	0	12
June Backyard Pot-Luck	1/8	6/9	6	3	33
July Support Meeting	0/0	3/4	2	0	9
August Support Meeting	0/2	2/6	2	0	12
September Neurologist	0/3	5/9	9	0	26
October Candle Light Vigil Chile Feast	0/9	9/18	6	2	44
November Support Meeting	0/2	4/8	4	2	20
December Cookie Exchange	0/0	4/3	2	0	9
January Support Meeting	0/2	5/8	2	3	20
					260

APPENDIX B

PARENT INTERVIEW GUIDELINE

PARENT INTERVIEW GUIDELINE

1. Was your child's head injury classified as:

   MILD MODERATE SEVERE

2. How old is your child? _____

3. Where is your child residing at present?

   _____Local Hospital

   _____Home with the family

   _____Nursing Home IN or OUT of state

   _____Rehabilitation Facility out of state

   _____Other _____

4. Do you attend support meetings regularly? YES NO

   IF NO, WHY NOT _____

   _____

   _____

   _____

5. How did you find out about the support group?

   _____

   _____

   _____

APPENDIX C

PARENT INTERVIEW RESULTS

PARENT INTERVIEW RESULTS

1. Was your child's head injury classified as mild, moderate, or severe?

Mild	0
Moderate	7
Severe	7

2. How old is your child?

Number	Years
2	5 years
2	6 years
1	7 years
2	8 years
3	9 years
1	11 years
2	12 years
1	14 years
14	8.6 MEAN AGE

3. Where is your child residing at present?

__0__ Local Hospital

__5__ Home with Family

__5__ In state nursing home

__1__ Out of state nursing home

__2__ Rehabilitation Facility

__1__ Home for the Mentally Handicapped

4. Do you attend support meeting regularly?

YES	NO
1	13

NO. OF PARENTS	REASONS
9	Meetings are too stressful. It is all they can do to handle their own difficult situation without taking on the burden of others.
6	Felt the emphasis of the group focuses on the needs of young adults and not children.
4	Guest speakers do not speak on issues relating to children.
4	Felt it is too late for a support group to help them. Their children are permanently living out of the home. They are trying to put their lives back together and do not wish to be reminded about the difficulties with their child. * Ironically, none of these four wished to have their names removed from the mailing list.
3	Did not find out about the support group until their child was well on the road to recovery. They stated they could have used a support group at the time of injury but do not need a support group now. All three parents did state that they wished to remain on the mailing list to receive updated information.
2	Have no way to transport their child or any one to stay home with their child. Both were single parents.
1	Felt support groups were composed of people who would rather "bitch and complain" than take responsibility for what life had handed them.

How did you find out about the support group?

NO OF PARENTS	Where
8	Classroom Teacher
2	Newspaper Calendar
2	Community Calendar
1	Friend
1	Hospital Personnel

APPENDIX D

PHONE ROSTER
JANUARY 1989 - JANUARY 1990

Phone Roster

January 1989 - January 1990

Month	Survivor	Family Member	Prof	Other	Total
January	2	6	4	0	12
February	3	2	6	2	13
March	5	3	2	1	11
April	1	5	9	2	17
May	2	5	12	4	23
June	4	3	7	1	15
July	1	0	3	0	4
August	2	5	4	1	12
September	1	8	4	1	14
October	8	12	16	4	40
November	1	13	3	0	17
December	5	4	2	1	12
January	2	2	3	2	9
Total	37	68	75	19	199
Mean	2.8	5.2	5.8	1.4	15.1

APPENDIX E

INCOMING PHONE DOCUMENTATION

HEAD INJURY SUPPORT GROUP
INCOMING PHONE DOCUMENTATION

_____Professional
_____Provider
_____Survivor
_____Family member
_____Other_____

Date:_____

Name:_____

Title:_____

Company:_____

Address:_____

City:_____State:_____Zip:_____

Work Phone:_____Home Phone:_____

Survivors and Family Members:

Relation to head-injured survivor:_____

Injury Cause:_____

Date of birth:_____Injury Date:_____

Age at injury:_____Sex:_____Coma:_____

Purpose of call:

_____

_____

How did you hear about the support group?

How:_____When:_____

APPENDIX F

NEW MEMBERSHIP APPLICATION

NEW MEMBERSHIP APPLICATION

_____Professional
_____Provider
_____Survivor
_____Family member
_____Other_____

Date:_____

Name:_____

Title:_____

Company:_____

Address:_____

City:_____State:_____Zip:_____

Work Phone:_____Home Phone:_____

Survivors and Family Members:

Relation to head-injured survivor:_____

Injury Cause:_____

Date of birth:_____Injury Date:_____

Age at injury:_____Sex:_____Coma:_____

Do you wish to volunteer?

_____Telephone committee
_____Phone Committee
_____Legislative Committee
_____Refreshments
_____Membership Committee
_____Speaker's Committee
_____Publicity Committee
_____Not at this time

How did you hear about the support group?

How:_____When:_____

APPENDIX G

"HEAD SMART"

"HEAD SMART"

1. How often does a head injury occur in the United States?

    1. Every 5 minutes
    2. Every minute
    3. Every fifteen seconds

2. How often does someone become "PERMANENTLY" disabled from a head injury?

    1. Every hour
    2. Every Day
    3. Every five minutes

3. What causes the most head injuries?

    1. Sports accidents
    2. Motor vehicle crashes
    3. Falls

4. What is the leading killer and cause of disability in children and young adults.

    1. Heart disease
    2. Head injuries
    3. Cancer

5. What is the "Ultimate Cure" for a head injury?

    1. Long term Rehabil tation
    2. Millions of dollars
    3. Prevention

APPENDIX H

AUDIENCE RESPONSE SHEET

"HEAD SMART"
RESPONSE FORM

DATE:_____NUMBER PRESENT_____

SCHOOL OR ORGANIZATION_____

==========

RESPONSES

1. How often does a head injury occur in the United States?

   1. Every 5 minutes _____
   2. Every minute _____
   3. Every fifteen seconds _____

2. How often does someone become "PERMANENTLY" disabled from a head injury?

   1. Every hour _____
   2. Every Day _____
   3. Every five minutes _____

3. What causes the most head injuries?

   1. Sports accidents _____
   2. Motor vehicle crashes _____
   3. Falls _____

4. What is the leading killer and cause of disability in children and young adults.

   1. Heart disease _____
   2. Head injuries _____
   3. Cancer _____

5. What is the "Ultimate Cure" for a head injury?

   1. Long term Rehabilitation _____
   2. Millions of dollars _____
   3. Prevention _____

APPENDIX I

PROGRAM EVALUATION

Program Evaluation

Head Injury Awareness and Prevention Program

Date:_____Place:_____

In order to assess the education benefit of this presentation, please rate and comment. This information will be utilized in planning future programs.

GENERAL INFORMATION

YOUR DISCIPLINE OR SPECIALTY:

____EDUCATOR	_____PSYCHOLOGIST
____PRINCIPAL	_____SPEECH THERAPIST
____CITE ADMINISTRATOR	_____OCCUPATIONALTHERAPIST
____NURSE	_____HEAD-INJURED PERSON
____PHYSICIAN	_____FAMILY MEMBER
____CASE MANAGER	_____OTHER_____
____BOARD MEMBER SERVICE ORGANIZATION	

OVERALL PRESENTATION

5=Excellent 4=Very Good 3=Average 2=Fair 1= Poor

Preparation	5	4	3	2	1
Slide presentation	5	4	3	2	1
Appropriate for audience	5	4	3	2	1
Handouts provided	5	4	3	2	1
Length of presentation	5	4	3	2	1

GENERAL COMMENTS:

APPENDIX J

STATE PAMPHLET

Head Injury Association of (State) Membership Application

Name _____

Address _____

_____

Telephone _____ Bus. _____

Type of Membership

- ☐ Basic $25
- ☐ Supporting $50
- ☐ Century Club $100
- ☐ Patron $500
- ☐ Sponsor $1000 or more
- ☐ Courtesy – For those unable to afford the basic membership fee.

Please Check:

- ☐ Head Injured Person
- ☐ Family Head Injured Person: Relationship
- ☐ Professional: Field
- ☐ Friend of Head Injury Association of Nevada

Please make check payable to:
HEAD INJURY ASSOCIATION OF (STATE)
4074 Autumn Street
Las Vegas, Nevada 89120

Would you be willing to volunteer in some capacity?

☐ Yes, especially in _____

Donations for a membership or commemorative occasion may be made by sending your check to: The (state) in memory of:

_____

_____

_____

_____

All memberships or donations are tax deductible

State Logo

Return Address

Address Correction Requested
Do Not Forward

BEST COPY AVAILABLE

HEAD INJURY ASSOCIATION OF (STATE)

(State Logo)

Help for the Head Injured and their Family

(Address)

Helpline
(Phone)

What is a Head Injury?

Serious head injuries usually result in prolonged loss of consciousness or coma. While it may be brief, lasting only a few minutes, it may extend to days or weeks. If the period of coma is brief, recovery to full of nearly full function is likely; but as time in coma lengthens, emergence to a full alert state can take a long time. Intellectual impairment, speech problems, behavioral disorders and related physical disabilities can become realities. The individual and his family face a period of rehabilitation that can extend for years. Most head injuries happen as a result of accidents but similar problems can result from conditions such as encephalitis, lack of oxygen to the brain and cerebral hemorrhage.

What Is a Closed Head Injury?

A closed head injury occurs when the heads hits another surface, such as a windshield. The brain strikes the inside walls of the skulls and may be squeezed and twisted.
A closed head injury can cause widespread damage to the brain. Swelling of the brain after the injury occurs can cause even greater damage.

What is a Penetrating or Open Injury?

It occurs when an object, such as a bullet, goes through the scalp and skull into the brain.
This type of injury usually damages a specific area of the brain.

Goals:

To promote the goals of the National Head Injury Foundation, Inc. The Nevada Association will work to:

1. Increase public, family and professional awareness of the silent epidemic.
2. Advocate to achieve recognition of the problem of head injury and the needs of those who have suffered head injuries.
3. Create an information and resource center for head injury.
4. Develop a unifying structure to provide support for the survivors of head injury and their families.
5. Assist in the establishment of rehabilitation programs for the head injury population – from coma to community.
6. Raise monies to support research.
7. Prevention.

Prevention – The Ultimate Cure
Marilyn Spivack
Founder, NHIF

For information about meetings and activities contact the support group in your area.

Facts:

Every fifteen seconds someone receives a head injury in the United States: every five minutes, one of those people will die and another will become permanently disabled.

Traumatic brain injury is the leading killer and cause of disability in children and young adults.

Males are more likely to suffer serious head injuries females, and young males between 15 and 24 years have the highest rate of injury.

Child abuse accounts for 64 percent of infant head injuries.

Motor vehicle crashes cause one-half of all traumatic brain injuries will falls accounting for 21 percent, assaults and violence 12 percent, and sports and recreation 10 percent.

Primarily a disability of the young, traumatic brain injury takes a tremendous toll on society. The economic costs alone approach $25 billion a year.

Despite this tremendous toll on society, research into the control and treatment of traumatic brain injury receives less than one penny of every Federal dollar spent on medical research.

A survivor of a head injury typically faces 5 to 10 years of intensive services at an estimated cost in excess of 4 million.

Interagency Head Injury
Task Force Report
February 1989

APPENDIX K

PREVENTION PROGRAM PAMPHLET

PREVENTION
The Ultimate Cure

Marilyn Spivak
Founder, NHIF

Wear a safety belt every time you drive or ride in a car. Insist that every passenger in the car wear a safety belt.

Child safety seats should be used in cars for all children under 5 years.

Never drive while under the influence of drugs or alcohol or ride with someone under the influence.

Wear a helmet whenever you are on a motorcycle or moped. Use a helmet if you bicycle, skate, skateboard, play football or any sport that involves a high risk for a head injury.

Don't dive into unfamiliar water. Always know how deep water is before you dive or slide.

Watch children carefully, especially when they are in highchairs, stroller, shopping carts or places where they could fall. Use restraining belts whenever possible.

Be careful around your house. Use care with ladders and on stairs. Watch out for other hazards in your home, such as open cabinet doors overhead.

Never shake a child - or anyone else. This can cause brain damage.

Secure all firearms - keep out of a child's reach.

State Logo

Return Address

Address Correction Requested
Do Not Forward

HEAD INJURY PREVENTION PROGRAM

(STATE LOGO) *Head Injury Association of (STATE)*

(ADDRESS)

Helpline
(PHONE)

A program partially funded by (STATE) Department of Human Resources, Rehabilitation Division

The Head Injury Prevention Program

"You cannot mend, repair or stitch it, and when it is injured the damage is often irreparable."

- Jeffrey Englander, M.D.
From film "If Only..."

The above statement was made in reference to injuries of the brain. The best way to avoid the disastrous consequences of such an injury is to

PREVENT THE INJURY FROM OCCURRING

What is a Head Injury?

Serious head injuries usually result in prolonged loss of consciousness or coma. While it may be brief, lasting only a few minutes, it may extend to days or weeks. If the period of coma is brief, recovery to full of nearly full function is likely; but as time in coma lengthens, emergence to a full alert state can take a long time. Intellectual impairment, speech problems, behavioral disorders and related physical disabilities can become realities. The individual and his family face a period of rehabilitation that can extend for years. Most head injuries happen as a result of accidents but similar problems can result from conditions such as encephalitis, lack of oxygen to the brain and cerebral hemorrhage.

The Program:

In an effort to educate those at high risk for devastating accidents we offer presentations especially appropriate for elementary children and one for junior high and high school students in driver's training and health education classes. The presentation includes:

A stimulating slide presentation describing the consequences of a traumatic head injury received by a resident.

A Rehabilitation Professional to answer questions, and

A head-injured individual who "personalizes" the presentation by sharing his or her story.

For information or to request a presentation at your school or organization, please call or write:

Facts:

Every fifteen seconds someone receives a head injury in the United States: every five minutes, one of those people will die and another will become permanently disabled.

Traumatic brain injury is the leading killer and cause of disability in children and young adults.

Males are more likely to suffer serious head injuries females, and young males between 15 and 24 years have the highest rate of injury.

Child abuse accounts for 64 percent of infant head injuries.

Motor vehicle crashes cause one-half of all traumatic brain injuries will falls accounting for 21 percent, assaults and violence 12 percent, and sports and recreation 10 percent.

Primarily a disability of the young, traumatic brain injury takes a tremendous toll on society. The economic costs alone approach $25 billion a year.

Despite this tremendous toll on society, research into the control and treatment of traumatic brain injury receives less than one penny of every Federal dollar spent on medical research.

A survivor of a head injury typically faces 5 to 10 years of intensive services at an estimated cost in excess of 4 million.

Interagency Head Injury Task Force Report
February 1989

APPENDIX L

FACT SHEET

FACTS ABOUT HEAD INJURIES

Every fifteen seconds someone receives a head injury in the United States.

Every five minutes, one of those people will die and another will become permanently disabled.

Traumatic brain injury is the LEADING KILLER AND CAUSE OF DISABILITY in children and young adults.

Motor vehicle crashes cause one-half of all traumatic brain injuries.

A survivor of a head injury typically faces 5 to 10 years of intensive services at an estimated cost in excess of $4 million

Of those who survive, each year approximately 70,000 to 90,000 will endure life-long debilitating loss of function.

Over 2,000 individuals who survive a head injury each year will exist in a persistent vegetative state.

Child abuse accounts for 64 percent of infant head injuries.

Males are more likely to suffer serious head injuries than females.

For more information contact:

(State Name , Address and Phone)

Interagency Head Injury Task Force Report
February 1989
Department of Health and Human Services

APPENDIX M

SUPPORT MEETING ATTENDANCE

FEBRUARY 1990 - OCTOBER 1990

Meeting Attendance

February 1990 - October 1990

Month	Pediatric Survivor or Family Member	Adult Survivor or Family Member	Prof.	Other	Total
February Support Meeting	0/1	6/8	1	2	18
March Support Meeting	0/1	2/6	2	0	11
April Support Meeting	0/2	8/10	1	0	21
May Psychologist	0/2	5/12	4	4	27
June Backyard Pot-Luck	1/5	6/9	6	3	33
July Hall of Fame Party	0/0	4/8	2	2	12
August Support Meeting	0/3	2/5	2	0	12
September Lawyer	2/3	7/12	9	3	36
October Candle Light Vigil Chile Feast	2/9	12/27	7	5	62
				Total	232
				Mean	25.7

APPENDIX N

PHONE ROSTER

FEBRUARY 1990 - OCTOBER 1990

Phone Roster

February 1990 - October 1990

Month	Survivor	Family Member	Prof	Other	Total
February	2	4	6	1	13
March	2	4	3	0	9
April	4	3	6	3	16
May	2	8	10	4	24
June	5	9	11	2	27
July	4	10	12	2	28
August	7	10	17	3	37
September	6	15	18	5	44
October	9	22	20	18	69
Total	41	85	103	38	267
Mean	4.5	9.4	11.4	4.2	29.7

APPENDIX O

PHYSICIAN'S SURVEY

(Physician's Name)
(Physician's Address)
(Physician's Specialty)
(Physician's Phone)

_____Please include my name in the directory.

_____DO NOT include my name in the directory.

_____The above information is correct.

_____Please make the following changes.

Name_____

Address_____

_____

Phone_____

Please circle: I would like to be listed under:

Neurologists Neurosurgeons Physical Medicine

Other_____

I accept: Medicaid Medicare Insurance

Additional Instructions._____

_____

_____Please leave my name on the mailing list as I regularly share information about the Support Group with my patients.

_____Please remove my name from your mailing list.

Signed_____Date_____

APPENDIX P

CALENDAR OF PRESENTATIONS

Calendar of Presentations

Day	Fourth Grade	Fifth Grade	Sixth Grade	Service Organizations
5/1	0	0	0	Kiwanis Club
5/3	0	0	0	Women's League
5/7	0	0	0	Key Club
5/9	0	0	0	PEO Chapter
5/14	0	0	0	Key Club
5/21	0	0	0	Human Relations Club
5/24	0	0	0	Christian Youth
5/27	0	0	0	Catholic Youth
6/11	2	0	0	Catholic Women
6/12	0	3	0	Shriners
6/13	2	0	2	0
6/14	3	0	3	0
6/15	0	0	2	Junior League
6/17	0	0	0	Christian Youth
6/18	3	0	0	Women's League
6/19	0	0	3	0
6/20	0	0	2	Catholic Youth
6/21	0	0	1	0
7/1	0	0	0	Christian Congregation
7/2	3	0	0	PEO Chapter
7/3	3	0	2	Knights of Columbus
7/8	0	0	0	Christian Youth
7/9	0	3	1	Morman Youth
7/10	0	3	0	0
7/11	0	3	2	0
7/12	0	0	3	0
7/16	0	0	4	0
8/1	4	0	0	Morman Youth
8/2	2	2	0	Electrical Workers
8/5	0	0	0	Christian Women
8/6	4	0	0	Off Road Enthusiasts
8/7	2	2	0	Public Employees
8/9	0	2	3	Christian Youth
8/12	0	0	0	Christian Youth
8/13	0	2	2	Morman Youth
8/14	0	0	1	Christians & Jews
8/15	0	0	0	Hospital Volunteers
9/17	0	0	0	Key Club
9/20	0	0	0	Human Relations Club
10/2	0	0	0	Catholic Women
10/28	0	0	0	National Safety Council
Total	28	20	21	33

APPENDIX Q

SAMPLE PRESS RELEASE

Sample Press Release

FOR IMMEDIATE RELEASE

The Head Injury Association of (State) will have their monthly support meeting at (Place) on (Day and Date) at (Time). This month the quest speaker will be (Name). The discussion will center around (Topic). If you would like more information or know someone who has suffered a head injury and needs assistance, please call (Phone Number) for more information.

Every fifteen seconds someone in the United States receives a head injury. Don't be a statistic, BE HEAD SMART, wear a helmet when your bicycling, skating, or skateboarding.

APPENDIX R

PRESS RELEASE CALENDAR

Press Release Calendar

Release Mailed	Speaker or Event	Date of Meeting
May 2, 1990	Psychologist	May 16, 1990
June 6, 1990	Pot-Luck Pool Party	June 20, 1990
July 15, 1990	Pre-Season Football Start-up Party	July 29, 1990
August 1, 1990	Support Meeting	August 18, 1990
September 7, 1990	Lawyer	September 19, 1990
October 10, 1990	Candlelight Vigil	October 26, 1990

APPENDIX S

A HEAD INJURY PREVENTION PROGRAM
FOR SCHOOL CHILDREN

A Head Injury Prevention Program For School Children

50 Minute Presentation

Outline

Introduction (5 minutes)

* Introduction of Presenters
* Definition of head injury
* Statistics of head injury

Slide Presentation (20 Minutes)

* Slide presentation
* Questions and Answers

Prevention and Safety Instructions (20 minutes)

* Presented by a Skateboard, bicycling, or roller skaking enthusiast
* Helmet and safety gear display

Safety Quiz

* Head Smart (5 minutes)

** All participants receive a head injury prevention pamphlet with safety tips and national statistics on head injuries, and a safety sheet for bike riding.

** Teachers receive the same handout plus handouts from the New York Head Injury Association entitled, "Teacher Alert - Head Injury? - Difficulty at School?" and "Because There Might Be More To A Head Injury Than You Thought".

APPENDIX T

A HEAD INJURY PREVENTION AND AWARENESS PROGRAM
FOR SERVICE ORGANIZATIONS

A Head Injury Prevention and Awareness Program For Service Organizations

50 Minute Presentation

Outline

Introduction (5 minutes)

* Introduction of Presenters
* Definition of head injury
* Statistics of head injury

Slide Presentation (30 Minutes)

* Slide presentation
* Questions and Answers

Prevention and Safety Instructions (10 minutes)

* Helmet and safety gear display
* The need for safety programs with children

Safety Quiz

* Head Smart (5 minutes)

** All participants receive a head injury prevention pamphlet with safety tips and national statistics on head injuries, and a handout from the New York Head Injury Foundation entitled, "Because There Might Be More To A Head Injury Than You Thought".

APPENDIX U

PHYSICIAN'S MAIL CALENDAR

Physician's Mail Calendar

Notices of Meetings

Date Mailed	Speaker or Event	Date of Meeting
May 2, 1990	Psychologist	May 16, 1990
May 15, 1990	Pamphlets Delivered	
May 16, 1990	Pamphlets Delivered	
May 17, 1990	Pamphelts Delivered	
May 18, 1990	Pamphlets Delivered	
May 22, 1990	Pamphlets Delivered	
June 6, 1990	Pot-Luck Pool Party	June 20, 1990
July 15, 1990	Pre-Season Football Start-up Party	July 29, 1990
August 1, 1990	Support Meeting	August 18, 1990
September 7, 1990	Lawyer	September 19, 1990
October 10, 1990	Candlelight Vigil	October 26, 1990
October 15, 1990	Survey Mailed	